



*Making Sense of YACDS:*

*Young Adult Complex Disability  
Service*

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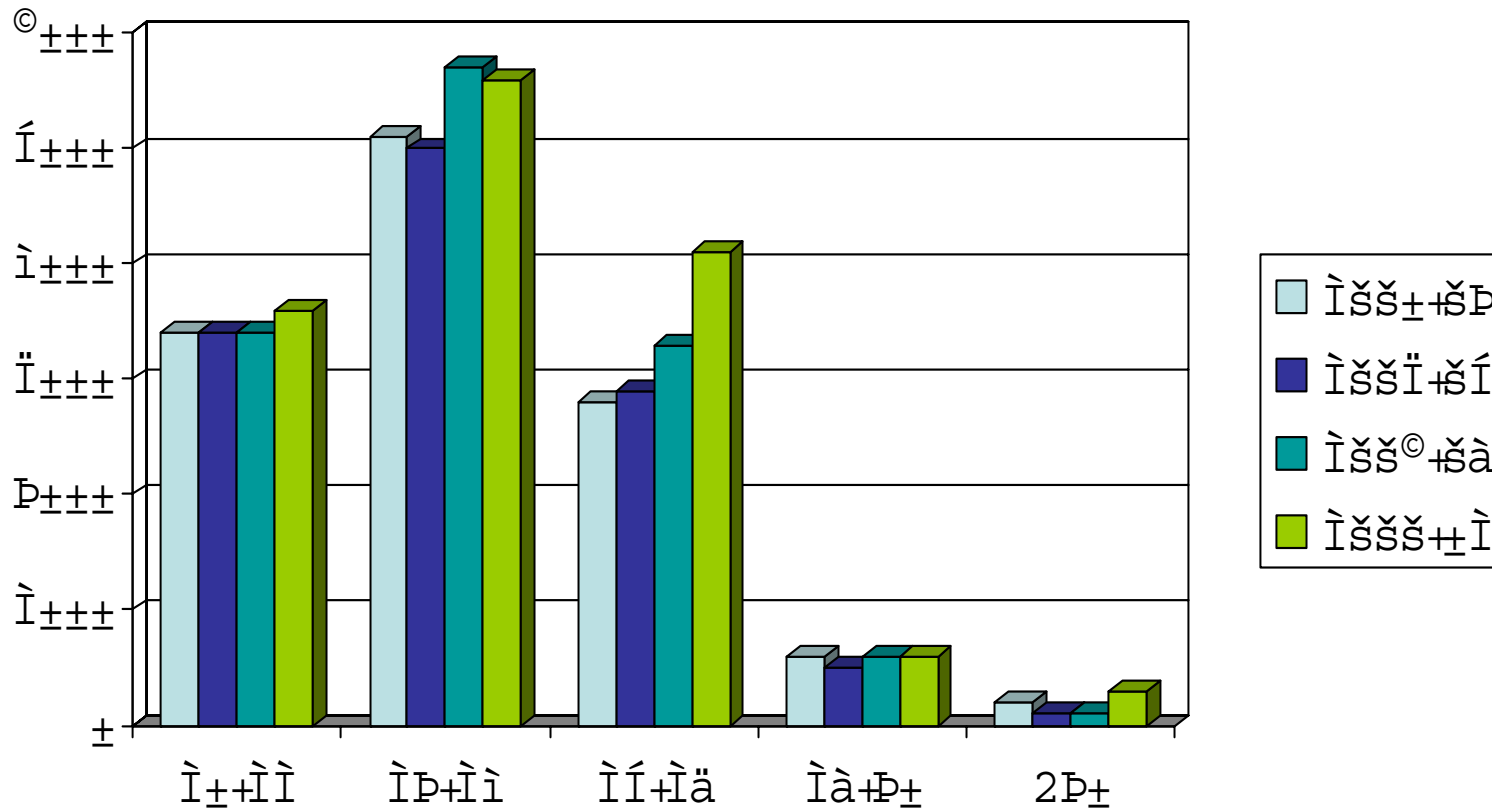
**St Vincent's**

*Continuing the Mission of  
the Sisters of Charity*

# Transition in Victoria –from children’s to adult health services



Many young adults with complex disabilities have continued to receive health care at the Royal Children’s Hospital (RCH)



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## DHS - Paediatric Transition Process Project 2005



- “Complex disabled patients appeared to be in limbo”  
(Paediatric Review – DHS Victoria 2002)

### Aims:

- To facilitate the routine transition of young adults from the RCH to the adult health service system.

### Assumptions:

- Young adults with complex medical needs and/or developmental disabilities have a right to receive appropriate care within the adult public hospital system
- Care to be funded through the standard funding streams

## DHS - Paediatric Transition Process Project 2005



### Outcomes:

- Successfully transitioned 11 young adults from RCH to SVH and RMH
- Sub-acute service environment most appropriate for long term, episodic medical care
- Sustainable clinics developed at SVH and the RMH
- Transition processes documented

## Cerebral Palsy - Definition

- Is a well recognised neuro developmental condition beginning in early childhood and persisting through the lifespan
- Bax, 1964 – *A disorder of movement and posture due to a defect or lesion of the immature brain*

## Cerebral Palsy – a quick medical refresher



- Gastro-oesophageal disease
- Lung disease
- Dental disease
- Osteoporosis
- Psychological and psychiatric problems
- Orthopaedic problems
- Saliva control problems
- Incontinence
- Spasticity
- Associated impairments
  - Epilepsy
  - Hearing problems
  - Visual problems
  - Cognitive deficits

## Importance of Transition



- *70% of young people with cerebral palsy will survive to adulthood*
- *Suggests to young people and their families that living into adulthood is a realistic expectation*
- *Encourages self responsibility of the young adult in managing own health needs*
- Stevenson et al Dev Med Child Neurol 1997
- Blum et al J Adolesc Health 1993

## Aim of YACDS



- To assist young adults with complex medical/physical needs, and their families, to navigate and integrate into the adult health care system
- Additionally;
  - Ongoing contact with clients to be maintained
  - Provide specialist assessment for young adults who have not accessed the health care system for a period of time



## Model of Service Delivery



- Client / Family centred
- Multidisciplinary team
- Joint assessments
  - Initial assessment on average takes 1.5 hours
- Delivery setting
  - Outpatients
  - Community

## Eligibility Criteria



- Age
  - Under 40
  
- Disability
  - Must have physical component
  - Exclusion, mental health/intellectual disability only
  
- Complexity
  - Medical and physical
  - Exclusion, behavioral/psychosocial complexity only
  - Exclusion, people currently receiving Intrathecal Baclofen
  
- No regional exclusions

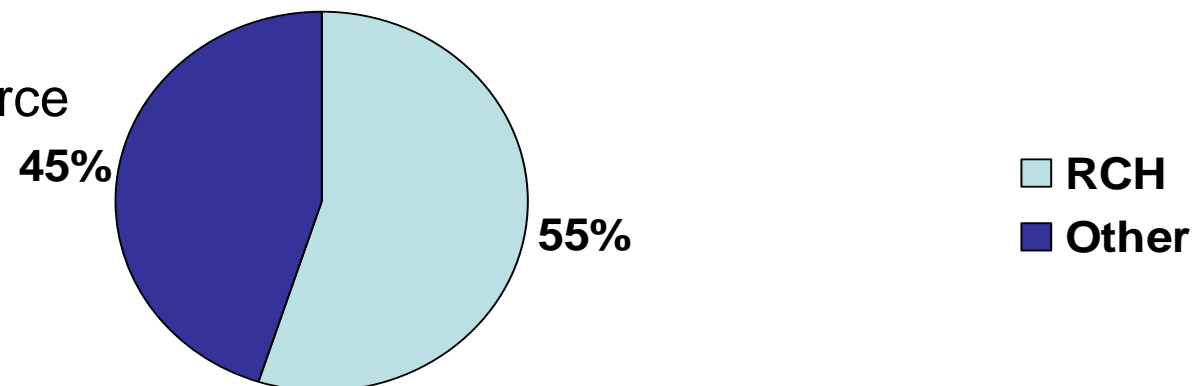
## St Vincent's YACDS – number of patients and referral source



Number of patients = 47 ( as at March 2007)

- 80% diagnosis cerebral palsy
- 92% aged between 16 – 25
- Trend towards self referral

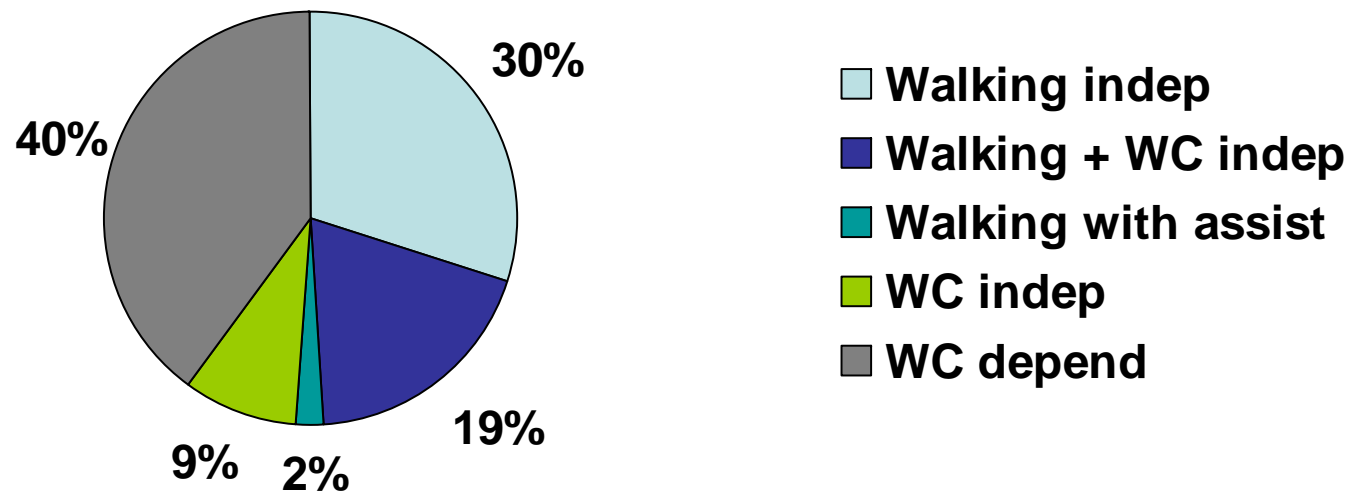
Referral source



# St Vincent's YACDS – functional status



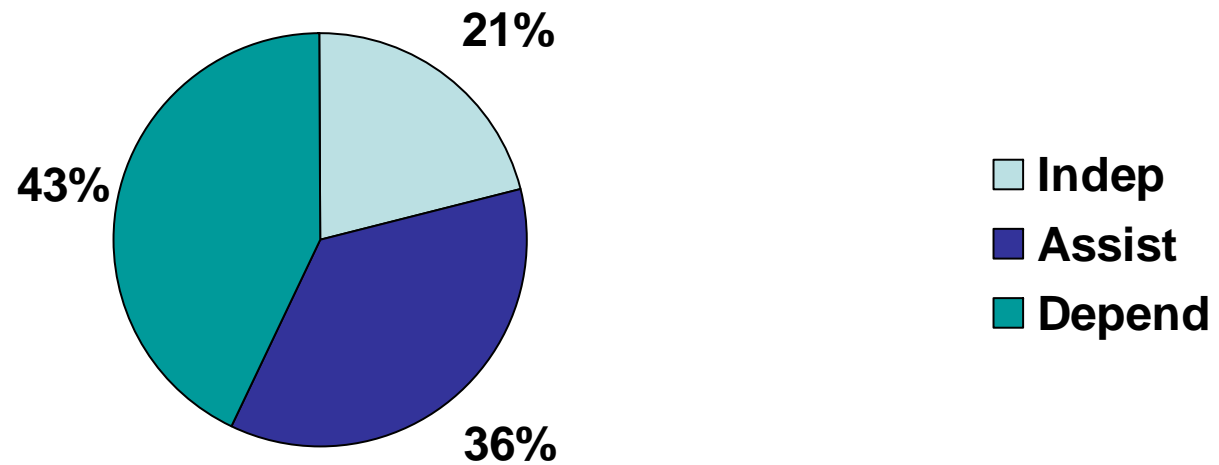
MOBILITY – largest group is wheelchair dependent



# St Vincent's YACDS – functional status



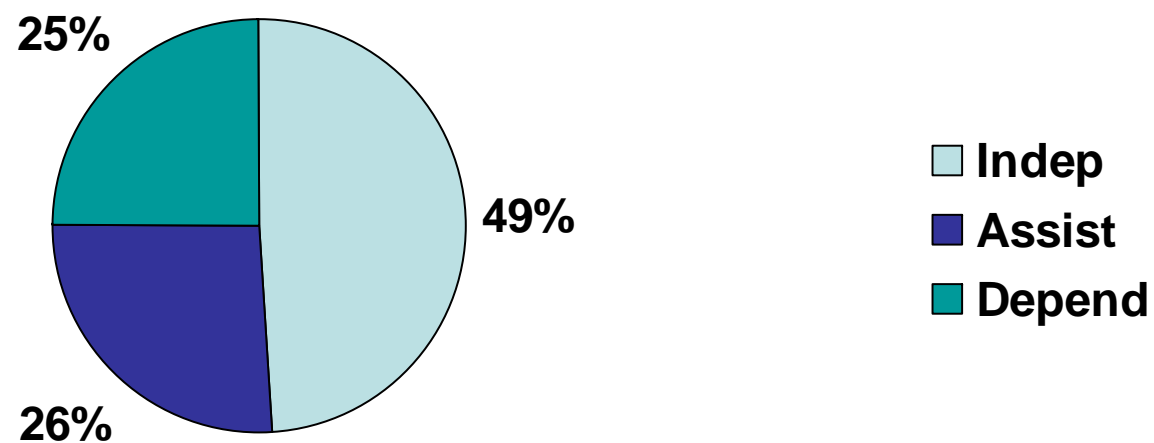
SELF CARE – largest group are dependent



# St Vincent's YACDS – functional status



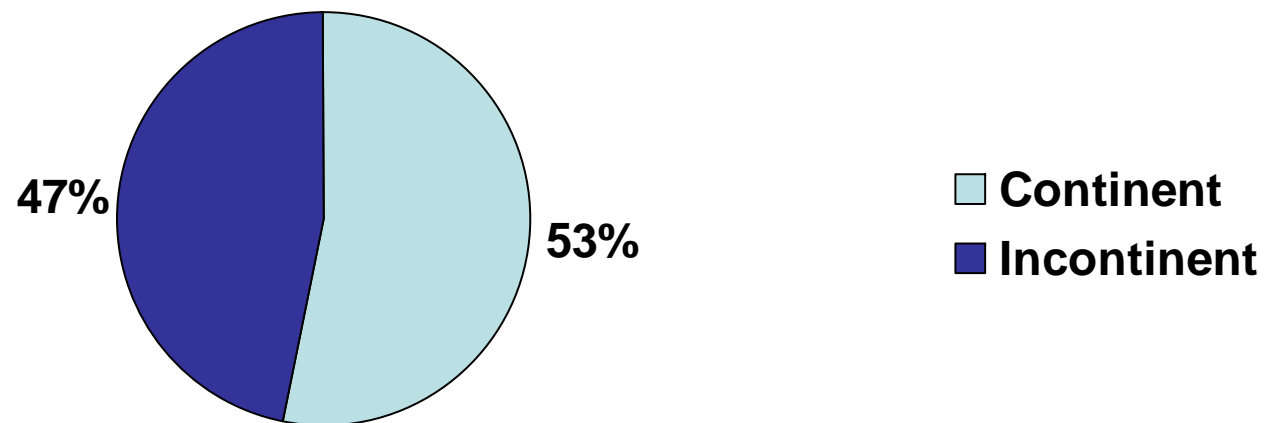
## COMMUNICATION



# St Vincent's YACDS – functional status



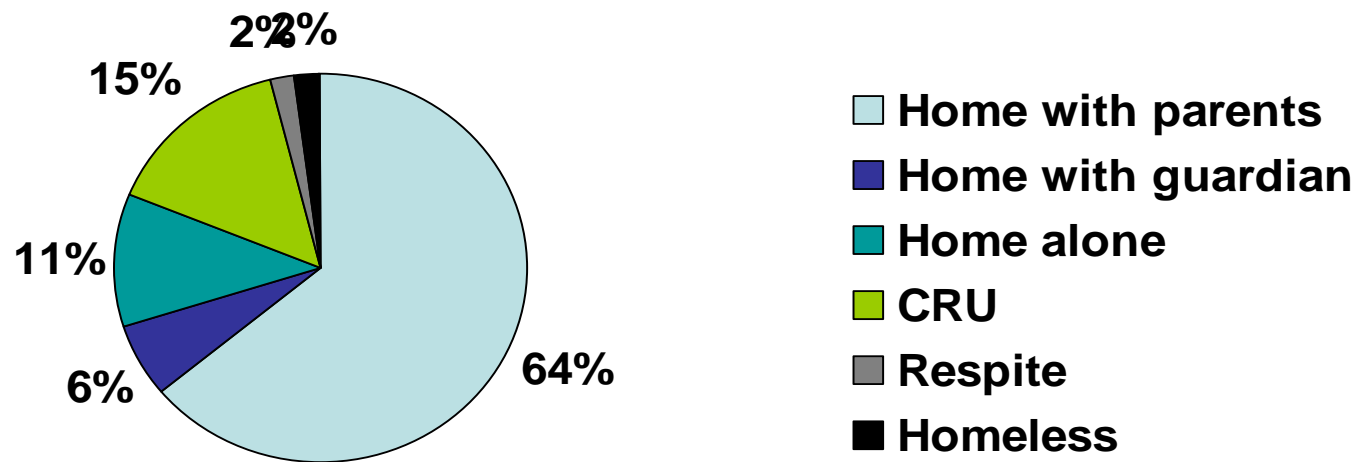
## CONTINENCE



# St Vincent's YACDS – living arrangements



Most live at home with parents

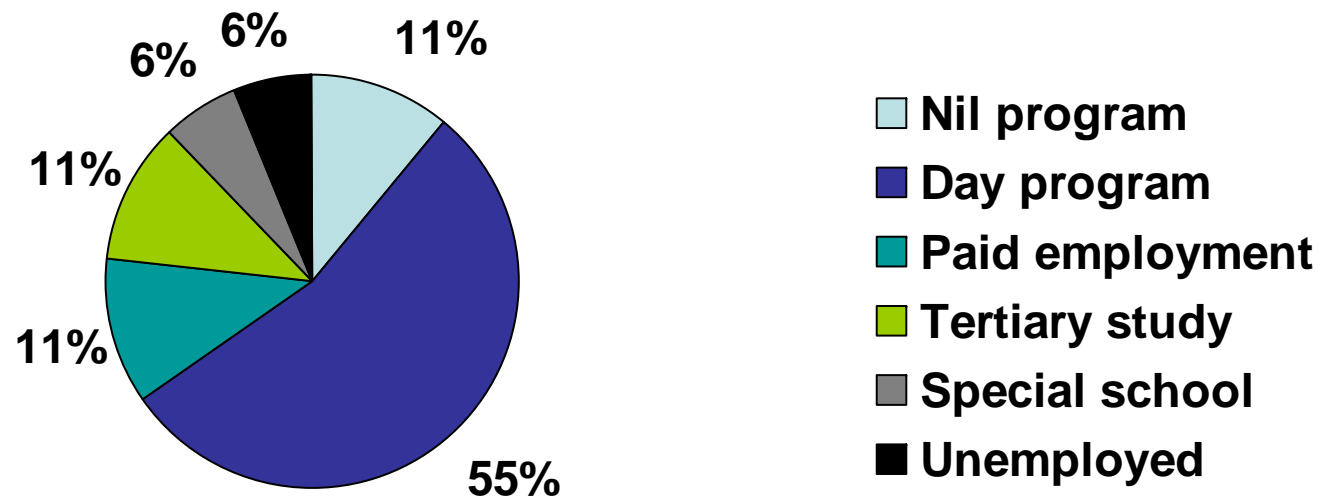




# St Vincent's YACDS – vocational status



Mostly involved in day programs



## St Vincent's YACDS – presentation of associated conditions



- Intellectual impairment 60%
- Epilepsy 36%
- Psychiatric/ behavioural 34%
- Vision impairment 30%
- Asthma/CLD 23%
- Gastrointestinal 19%

## YACDS Patient Outcomes



– Interventions Attended	
▪ St Vincent's Allied Health	60
▪ St Vincent's Based Clinics	32
▪ Referrals External to St Vincent's	31
– SVH Admissions	13
– Deaths	5 (11%)

# Cerebral Palsy – Health & Social Issues in Adulthood



- *Use of, and exposure to, health and social services markedly decreases after leaving school*
- *Carer anxiety regarding provision of services, and frustration in obtaining information about help*
- *Communication poor between agencies providing care and between the agencies and the young person or carer*
- *Greater social isolation*

Stevenson et al. Dev Med Child Neurol. 1997 May;39(5):336-42

Ng et al. J Orthop Surg (Hong Kong) 2003 Jun;11(1):80-89

Cathels et al. Med J Aust. 1993 Oct 4;159(7):444-6

## Issues surrounding complex disabled patients



- Patient supports
  - Differences in resources and funding
- Decision making responsibilities
  - Expectations of self management
- Unfamiliar conditions and presentations
- The role of the GP
- Lack of friendship networks
- End of life issues

## Some of the challenges ahead:

- Future services and staffing implications
  - Clinic growth
  
- Identify and address gaps
  - Wheelchairs and seating
  - Carer support
  - Orthopaedic surgery
  - Intrathecal baclofen
  - Support of GP's
  - Sexuality
  
- Research
  - Ageing and CP